

Appendix C

Contacts

Professionals Who Serve Families Affected by NTDs

A variety of medical specialists treat children with NTDs. The treatment for a child with spina bifida usually requires a multi-disciplinary approach, including surgeons, physicians, and therapists. One individual, often a pediatrician, will coordinate a child's treatment program. In addition, support staff will be needed to offer time, information, and comfort to parents learning that their child will suffer from a condition like an NTD. This experience and adjustment can cause an enormous amount of stress and grief for the family involved. Following is a list of medical specialists who treat children with NTDs and who can help parents make appropriate choices for themselves and their children. In this day of managed health care, most patients must be referred by their primary care provider to any of these specialists.

Dieticians and Nutritionists are trained to provide nutrition assessments and counseling to ensure adequate nutrition and promote the development of self-feeding skills.

Education specialists are available in schools and private practices to guide families whose children have learning disabilities and other special education needs.

Family physicians have a broad range of training that includes general medicine, surgery, gynecology, and pediatrics. They are primary care physicians who provide medical diagnosis, treatment, and guidance for an individual or a family on a long-term, continuing basis.

Genetic counselors are health professionals who use the information from genetic studies and geneticists to answer questions for and to give guidance to families about inherited disorders and diseases.

Geneticists deal with heredity and its variations. They look at genes from the body's cells to identify certain inherited disorders and diseases.

Internists are physicians who are trained in the general medical care of adults. They diagnose and treat nonsurgical diseases of the body. Providing long-term, comprehensive care for adults in the hospital as well as the office, they are considered primary care physicians. Internists may also receive additional training to specialize in certain areas of medical care. Some examples are cardiologists who treat heart disease; pulmonologists who treat lung disease; and endocrinologists who treat diseases of the endocrine system, such as thyroid problems and diabetes.

Mental health professionals include **psychiatrists (MDs), psychologists, psychiatric clinical nurse specialists, psychiatric social workers**, and other mental health counselors who help individuals and families deal with the emotional stress that frequently accompanies long-term medical problems and disabilities.

Neurologists are physicians trained to diagnose and treat with medicine diseases and problems with the nervous system, which includes the brain, the spinal cord, and the nerves in the body. They deal with conditions such as seizure disorders and migraine headaches.

Neurosurgeons are physicians who perform surgery on people having problems with the brain, the spinal cord, or the nerves in the body. They often operate on spinal defects to “repair” or “close” them and put in shunts to relieve pressure on the brain in children with hydrocephalus.

Nurse practitioners are nurses who have received additional education and training to provide primary health care to individuals or families. They usually work with one physician or a group of physicians and provide treatment and guidance for a variety of conditions and diseases. Nurse practitioners can also be specialized to provide health care for certain patients, such as children, or certain medical problems, such as neurological diseases and disorders.

Obstetricians and Gynecologists are physicians who have expertise in the normal and abnormal functions of the female reproductive system and may provide information on family planning, pregnancy, and birthing options.

Occupational therapists help people with physical and mental challenges to achieve their maximum level of performance. They help people with physical, developmental, social, or emotional problems to learn new ways of coping with those problems so that they can be more independent, productive, and happy with their lives.

Orthopedists are specialized physicians who are trained in the care of patients with musculoskeletal problems. They may treat, with or without surgery, conditions involving the bones and the muscles of the body. Congenital deformities of the bone and muscle, injuries to the bone and muscle, and infections of the bone and muscle are some of the conditions with which they deal.

Orthotists are skilled in the straightening or correction of a deformity. They develop splints, braces, and other physical devices to help patients retain or attain as much structure and function of the body as possible.

Pediatricians are physicians who specialize in children’s health issues.

Pharmacists are responsible for monitoring medication therapy and helping patients to manage that therapy. They work closely with other health care professionals to ensure the best outcome of medication therapy.

Physical therapists are health care professionals who have been trained to assess and improve movement and function of the body and to relieve pain. They work with people who have injuries or disabilities and use a variety of therapeutic physical agents, including heat, light, water, electrical stimulation, massage, and exercise.

Physician assistants are similar to nurse practitioners. They work with one physician or a group of physicians to provide primary health care to individuals or families. They can also be specialized to provide care for certain patients and /or diseases or conditions.

Social workers are professionals who help patients and their families deal with the social, emotional, and some financial aspects of their medical problems.

Organizations That Serve Families Affected by NTDs

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American Academy of Family Physicians

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Web site: <http://www.aafp.org>

American College of Obstetrics and Gynecology

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(202) 638-5577
Fax: (202) 484-5107
Web site: <http://www.acog.org>

American College of Physicians

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Web site: <http://www.acponline.org>

American Dietetic Association

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800/877-1600
Web site: <http://www.eatright.org>

American Nurses Association

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(202) 651-7000
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Web site: <http://www.nursingworld.org>

American Pharmaceutical Association

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(202) 783-2351 - Fax
Web site: <http://www.aphanet.org>

American Society for Nutritional Sciences

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(301) 634-7892 - Fax
Web site: <http://www.asns.org>

Association of State and Territorial Public Health Nutrition Directors

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Association of Women's Health, Obstetric, and Neonatal Nurses

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(202) 728-0575 - Fax
Web site: <http://www.awhonn.org>

Centers for Disease Control and Prevention

National Center on Birth Defects and
Developmental Disabilities

1600 Clifton Road

Mailstop E-86

Atlanta, GA 30333

(404) 498-3800

Web site: <http://www.cdc.gov/ncbddd>

Healthy Mothers Healthy Babies

121 North Washington St., Suite 300

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Web site: <http://www.hmhb.org>

March of Dimes Birth Defects Foundation

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Web site: <http://www.modimes.org>

**National Coalition of Hispanic Health and
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Web site: <http://www.hispanichealth.org>

**National Rehabilitation Information Center
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Web site: <http://www.naric.com>

Shriners Hospitals for Children

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Web site: <http://www.shrinershq.org>

Spina Bifida Association of America

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Potential Partners in Your Community

Note: This is not an exhaustive list of possibilities. Each community has its own unique set of resources. Customize a database of interested parties for your own community. Begin now and add to it throughout the campaign.

Partners Already Involved in the Folic Acid Issue

C *National Task Force Members*

American Academy of Family Physicians
 American Academy of Pediatrics
 American College of Physicians
 American College of Obstetricians and Gynecologists
 American Dietetic Association
 American Nurses Association
 American Pharmaceutical Association
 American Society for Nutritional Sciences
 Association of Maternal and Child Health Programs
 Association of State and Territorial Public Health Nutrition Directors
 Centers for Disease Control and Prevention
 Healthy Mothers Healthy Babies
 March of Dimes Birth Defects Foundation
 National Coalition of Hispanic Health and Human Services Organizations
 Shriners Hospitals for Children
 Spina Bifida Association of America

Partners Who Have Women as Customers, Members, Clients, or Employees

C *Health Care Links*

Community clinics (e.g., teen health, maternal support)
 Family planning service providers
 Genetic counselors
 Home visitors & other community workers (e.g., Meals on Wheels/AFDC/Social Workers)
 Hospitals
 Infertility clinics
 Lay midwives
 Managed care providers (HMOs)
 Nurses
 Parish nurses
 Pharmacists
 Physician assistants

Physicians (pediatricians, OB/GYNS, internists, family practitioners, children's special health care services)
 Prenatal clinics
 Registered dietitians/ public health nutritionists (e.g., WIC)
 Specialized health/nutrition services (e.g., Indian Health Services health educators, Migrant Health Program)

C *Community Business Links*

Beauty salons
 Billing agencies (utility bill inserts)
 Bookstores
 Bridal fairs/ bridal registries
 Fitness clubs
 Food distributors
 Groceries/corner stores/farmer's markets
 Insurance companies
 Laundromats
 Mass merchandise retail stores
 Nonprescription drug manufacturers
 Nutrition stores
 Printing/copying companies
 Restaurants
 Retail and distribution outlets
 Video stores
 Weight loss centers

C *Other Community Links*

Children's Miracle Network
 City Hall/Marriage License Bureau
 Day care centers
 Girl Scouts
 Head Start Programs
 Libraries
 Local public and private schools
 Local or regional broadcaster's association
 Local or regional public relations clubs
 Parent Teacher Associations
 Preschools
 Red Cross
 Religious associations
 School boards
 Trade schools
 Unions

United Way
Universities

C *Public Forums*

Health fairs

Outdoor advertising venues (billboards, mass transit, malls)

Media:

 Television stations (networks and local cable access)

 Radio stations

 Newspapers

 Special-interest journals (e.g., Hispanic community newsletters)

C *Government Agencies*

 Governor's Office

 Maternal and Child Health Bureau

 Public assistance programs (e.g., AFDC, Food Stamps, Medicaid)

 Public health departments/ state prevention programs

 USDA, Food and Nutrition Service

 U.S. Food and Drug Administration